Personal Brief of D.K. Summerhayes, Director Canadian Cystic Fibrosis Fdn. (48)

(Brief follows App. 1 & 2)

APPENDIX I

Cystic Fibrosis.

Cystic Fibrosis is a hereditary chronic illness of a catastrophic nature. It is considered catastrophic because of the high costs in treatment. Cystic Fibrosis affects the lungs, digestive tract and execrine glands.

The major problem in treating cystic fibrosis is that of keeping the lungs clear of the thick sticky mucus which tends to clog the air sacs, thereby making breathing difficult for the child and putting undue strain on the child physically. This mucus must be thinned and removed from the lungs if the child is to live anywhere a normal life. This mucus also clogs the ducts leading from the pancreas to the stomach delivering the digestive juices to the stomach for proper digestion of food. These children, therefore, require digestive enzyme fed to them orally. In addition to the physical burden to the child, there is a mental burden, not only to the child, but to the parents and other children in families with children afflicted with Cystic Fibrosis. Therefore, I submit this brief regarding the cost, the care and treatment of these children.

Does not believe in Tax supported plan - individual should pay - contributory.

Indigent - Can receive good home assistance.

Medical indigents - require help.

believes med. profession should be able to apply - needs test.

APPENDIX II

The disease entity known as Cystic Fibrosis was first described in 1938. Prior to this period, children born with this condition usually dies within the first year of life, diagnosed as some other condition such as pneumonia. Since 1938, a great deal of progress has been made in treating the condition so that today the longevity of children suffering from Cystic Fibrosis has been increased - in some cases into adulthood.

The disease occurs in approximately one in every thousand births. Between 200 and 250 children are under treatment in the Province of Ontario and proportionately smaller numbers in other provinces. Treatment clinics are established in Halifax, Montreal, Toronto, London, Winnipeg,Edmonton,Vancouver and a new one in the Civic Hospital in Ottawa.

The condition affects the chest, pancreas, sweat glands, and liver. Accurate diagnosis is essential. The treatment involves drug therapy, inhalation equipment and physical therapy. The determining factor as to whether or not these children revolves around in early diagnosis and the management of the chest condition.

In 1959, a group of parents in Canada, inspired by success in the United States, organized the Canadian Cystic Fibrosis Foundation and received a national charter on July 15th., 1960. Since the founding of the Canadian Cystic Fibrosis Foundation, the organization has met with considerable success in interesting members of the medical profession and the public in the problems which we as a community face in connection with the treatment of these children. Seventeen Chapters have been organized and are carrying on an active program in Vancouver, Edmonton, Calgary, Regina, Winnipeg, Hamilton, Niagara Peninsula, Brantford, Kitchener-Waterloo, London, Toronto, Sudbury, Ottawa, Kingston, Montreal, Saint John and Halifax. There are two provincial organizations, The Cystic Fibrosis Association of Quebec, Inc., with its main centre of activity in the Montreal area, and the Cystic Fibrosis Society of Nova Scotia with its centre of activity in Hamilfax. Both these provincial groups are chapters and work closely with the National Foundation.

The problems of this organization may be divided into four areas:

1. The cost of drugs and inhalation therapy equipment. This is an essential part of the management of the

condition, when in the majority of cases the life of the child depends upon the supply of the appropriate drugs recommended by the Paediatrician after a careful diagnostic process. The costs of these drugs are high and can amount to, between $50 and $150 a month, with a rough average of $75. a month, per child. The Foundation has done much to reduce the cost of drugs through working with drug houses in the various provinces. The cost quoted above, however, is based on the reduced cost of the drugs secured through hospital out-patient clinics or wholesale drug houses. Inhalation therapy equipment is also an essential part of treatment. No Cystic Fibrosis child can progress without it. Our Foundation, in the light of this, has a policy that they will supply the necessary tent, compressor and face mask to any Canadian Child requiring it, regardless of whether or not the parents can pay for it. This has created a heavy financial drain, but our work must con inue.

2. The development of Adequate Treatment Centres.

It is the recommendation of both the Medical and the Research Advisory Committees to the Foundation that such centres should be established in university hospital settings. There are many reasons for this. The first is the use of already existing facilities in the Children's hospitals, such facilities as inhalation, and laboratory services in chemistry, bacteriology, haem[illegible] paediatric radiology, physical therapy, etc.

3. Clinical Research.

Although the disease entity was described in 1938, it is still not known exactly where the seat of the disease lies. It is known to be a genetically determined disease and, within the field of basic research, this is one of the major areas of investigation. Recognizing that Cystic Fibrosis is a chronic disease which requires supervision from infancy through adulthood, however, it is reasonable to expect that the ultimate control and stability of the disease in relationship to a particular individual may be found through the proper use of drugs. This places great importance on the necessity for clinical research or a clinical investigation program. In such a program, the effect of the various drugs utilized in drug therapy, and the type of inhalation therapy equipment, would be examined in relationship to the progress of the children attending the clinic. The researcher requires the clinic and the child, since he has no animal in which a comparable disease can be produced to give him a model for experiments.

A brave attempt has been made, with our limited funds in an approach to research. Six grants of $800 each were made last year to six medical students recommended by the Research Advisory

Committee. They worked under the guidance of the best medical men in the field across Canada. Two research grants were also made to the Children's Hospital of Winnipeg and the Montreal Children's Hospital, totalling $7,600.

4. Public Information.

The public knows little of the extent and seriousness of the Cystic Fibrosis problem and the urgent need for community and national efforts to fight it.

Our basic work, with the funds available, has only begun. Many practising physicians have not had the opportunity to become familiar with the diagnosis of the disease, or the positive treatment techniques which can often save the lives of Cystic Fibrosis Patients. Some standard medical dictionaries do not yet carry definitions of the disease and many paediatricians' texts still say the prognosis is hopeless.

This general state of unawareness can and must be overcome. We have established excellent liaison with the National Cystic Fibrosis Research Foundation in the U.S.A. They have advanced to the point where 50% of their cases are reaching their teens and 50 patients are now over 17 years of age. We are benefiting from their knowledge but we must press forward to match their achievements as we work to save the lives of Canadian Children.

BRIEFS

ON MEDICAL SERVICES INSURANCE

FOR THE CHRONICALLY ILL

The chronically ill person should be assisted through coverage by Ontario Hospital Insurance for out-patient care. This is particularly true of chronic illnesses of a catastrophic nature such as Cystic Fibrosis. Cystic Fibrosis is more completely described in Appendix I and II

Assistance for those afflicted with Cystic Fibrosis is required through Ontario Hospital Insurance to cover the out-patient cost of care as follows:

(a) Equipment. Inhalation therapy tents and face mask equipment required for treatment and well being of persons afflicted with Cystic Fibrosis. This equipment currently costs the Canadian Cystic Fibrosis Foundation approximately $200 per unit. This cost to an individual patient through a medical supply house would run substantially over $300 per unit. The Foundation has supplied a great deal of equipment however, since limited funds are available unless assistance to the patient is found elsewhere, this equipment may be in short supply. Hospital Insurance should be provided to cover the cost of this equipment as to date it has been considered to be one of the best holding treatments for those afflicted with Cystic Fibrosis.

(b) Drugs. Drug costs run anywhere from $50 to $150 per patient with an average of $75 to $100 per patient. The costs of these drugs adds a very heavy burden to parents of children afflicted with Cystic Fibrosis. The cost of drugs mentioned herein is based on a reduced cost through pharmacists willing to assist Cystic Fibrosis families by selling these required drugs at reduced mark-ups. A reasonable estimate at regular retail prices of the drugs including prescription fees would be considerably more than $100 per child. As these drugs are required over long periods, many such as Cotazyme - a digestive emzyme, Aquasol-E - a special vitamin supplement, double dosages of regular vitamin supplements and antibiotic treatments required over a long period, should definitely be covered under Ontario Hospital Insurance. Without these drugs, children afflicted with Cystic Fibrosis would have little chance of survival.

(c) Therapy. Physical therapy as required for these children to loosen the large amount of mucus caked to the lung tissue. This therapy must be carried out by the parents of the children afflicted after training while the children are in the hospital. During periods of extreme lungs infection professional therapy by trained nurses or physiotherapists is required. Many of these children at present, are hospitalized during the period of severe lung infection, however, many could be treated as well at home thereby reducing the cost to the Ontario Hospital Insurance Commission by the amount of roomaand board in the Hospital if therapy treatment was included for out-patient home care under the Ontario Hospital Insurance program.

(d) Clinical Treatment and Assessment. Treatment and assessment at out-patient clinics is essential for children afflicted with Cystic Fibrosis. This should include the cost of X-ray, cultures, pulmonary function tests and any other tests required from time to time for proper assessment. This should be covered for clinics, either in Ontario or other parts of Canada or outside Canada.

(e) Home-Maker Asssitance. Because of the extra heavy burden on the mother of children afflicted with Cystic Fibrosis, limited home-maker assistance should be provided, particularly in those homes where there are more than one child afflicted. This would allow the the mother to spend some time with the other children in the home, thereby relieving to some extent the emotional strain placed on these normal children.

Why is this Assistance Required?

(i) As outlined above and in the Appendices attached hereto, you will notice the extra heavy costs for the treatments to the family. This is particularly critical in families in the middle and lower income groups. This being the largest segment of the population, it necessarily follows that they will have the largest number of sCystic Fibrosis Children.

(ii) Increased life expentancy for these children through the provision of improved treatment and care because the costs are being met without the family being burdened financially, to the extent that they cannot provide total care for these children.

(iii) Many of these children are extremely bright and would become valuable citizens.

(iv) Travelling expenses to clinics and hospitals can be a sizable factor in the cost of trating these children. As regular assessment is vital to the well being of these children,

and clinics are currently only available at mid-teaching centres, these costs can mount. Representations should be made to the Federal Government to allow for deduction of these expenses from income as medical expenses. When referring to travelling expenses, I refer to reasonable expenses consisting of hotel, meals, and transportation..

In view of the foregoing, I respectively suggest that many of these costs could and should be included in any extension of hospital insurance in Ontario.